

ANA NJ

ACOUSTIC NEUROMA ASSOCIATION of NEW JERSEY

ANA/NJ Newsletter

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October 2022

ANA/NJ Virtual/Zoom Meeting February 27, 2022

Ten people attended the Zoom ‘Care and Share’ meeting on Sunday, February 27, 1-3 pm. Board members in attendance were Dave Belonger, Wilma Ruskin, Dick Barker and Donna Carides. Dave Belonger opened the meeting and welcomed everyone. Dave introduced Wilma Ruskin who asked that we each introduce ourselves by name, say where we live, and if we are pre- or post-treatment or Wait-and-Watch patients. The meeting was then opened for questions, observations and general discussion.



Dick Barker described his recent positive experience with the Signia BiCros system for single-sided deafness. He answered questions about his experience.

Dave Lavender discussed his issues with ‘dry eye’ and recommended using Xiidra, which is available by prescription.

Alex Fiorenza recommended using Shokz bone conduction headphones for helping with hearing issues when watching TV.

Phyllis Schreiber talked about the fact that she has been Wait-and-Watch for over 20 years.

There were various other comments and lively discussions. We are very grateful for Zoom until we can get back to ‘live’ meetings, hopefully later this year.

CROS Technology Reviewed

Thinking of trying CROS technology for remediation of single-sided deafness? Take a look at Dr. Hillary Snapp’s helpful review of the literature: “Nonsurgical Management of Single-Sided Deafness: Contralateral Routing of Signal,” *Jour of Neurological Surgery*, Vol.80 (April 2019). A free full text copy is available online at PubMed.gov.

Dr. Snapp writes: “Contralateral routing of signal (CROS) is the longest standing rehabilitation solution for individuals with single-sided deafness. The primary goal of CROS technology is to transfer the signal received at the deaf ear to the better hearing ear, thereby reducing the impact of the acoustic head-shadow. While surgical management of single-sided deafness is on the rise, CROS hearing aids offer a nonsurgical option to compensate for some of the deficits that occur when a listener is limited to a single ear. Limitations of early CROS devices resulted in poor adoption and acceptance in those with single-sided deafness. Following significant advances in both design and technology, the acceptance of CROS devices has increased in recent years. This paper reviews relevant literature in CROS application for the management of single-sided deafness.”

ANA/NJ

Acoustic Neuroma Association
of New Jersey

A Non-Profit Corporation

Website: www.ananj.org

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Notices!

● A special invitation. If you have administrative or technical skills and want to help other AN patients as you were helped, please think of joining the ANA/NJ Executive Board. The Board is essentially “electronic” these days via phone, email exchanges and periodic Zoom meetings. Call Wilma at 609-510-9039 if you want to help.

● *Newly Diagnosed Handbook* (February 2022) is the title of a new educational booklet issued by ANAUSA. The booklet (34 pp) is written by Dr. Matthew L. Carlson, MD, Professor of Otolaryngology and Neurosurgery at the Mayo Clinic, Rochester, Minnesota. The booklet is free to ANA members.

Acoustic Neuroma: A Brief Chronology

| | |
|-------|--|
| 1777 | First description (Edward Sandifort) |
| 1838 | Schwann cells identified (Theodore Schwann) |
| 1895 | First successful removal (Thomas Annandale) |
| 1917 | <i>Tumors of the Nervus Acusticus 1917</i> (Harvey Cushing) “The Father of Neurosurgery” |
| 1930s | Partial removals of large tumors |
| 1940s | Retrosigmoid total removals (Walter E. Dandy) |
| 1950s | Surgical microscope (William F. House) Translabyrinthine & Middle Fossa surgeries refined |
| 1967 | Gamma Knife prototype, Radiosurgery (Lars Leksell) |
| 1970s | Imaging by CT scanner |
| 1980s | MRI scanner era begins (Raymond Damadian) |
| 1983 | House-Brackmann facial nerve function scale First ANA Patient Survey in U.S. |
| 1987 | First Gamma Knife Center in U.S. (L. Dade Lunsford) Linear Accelerator (Linac) Radiotherapy option |
| 1988 | Gardner-Robinson Hearing scale |
| 1990 | Proton Beam (Loma Linda, CA) |
| 1991 | AN Consensus Development Conference (NIH) |
| 1993 | NF2 gene identified (G. Rouleau et al) |
| 1994 | Cyberknife (John Adler) |
| 2000s | Focus on preservation of facial function (Subtotal removals refined) Focus on preservation of hearing (Middle Fossa surgery, “Wait-and-Watch”) “ <i>Natural History of VS</i> ” 2006 (Sven-Eric Stangerup) |
| | Focus on genomic/molecular studies |
| 2010 | Penn ‘Quality-of-Life’ preservation scale (B. Shaffer) |
| 2018 | CNS/AANS treatment guidelines for VS |

Hearing Aids and Dementia

Dr. Frank R. Lin, Professor of Otolaryngology at the Johns Hopkins School of Medicine in Baltimore, MD, is heading the first randomized control trial “to see if hearing aids can safeguard seniors’ mental processes.” Funded by the National Institute on Aging, “the study has recruited nearly 1,000 people ages 70-84 with hearing loss. One group is provided hearing aids, while another group receives aging education [to manage diet, nutrition and exercise]. By early 2023, the study should provide definitive results on whether treating hearing loss will reduce the risk of cognitive decline. Hearing loss can make the brain work harder, forcing it to strain to hear and fill in the gaps. That comes at the expense of other thinking and memory systems. Another possibility: Hearing loss causes the aging brain to shrink more quickly. A third possibility is that hearing loss leads people to be less socially engaged, which is hugely important to remaining intellectually stimulated. If you can’t hear very well, you may not go out as much, so the brain is less engaged and active”¹

An article by Temma Ehrenfeld in the magazine *Healthy Hearing* surveys recent research in this area. She speculates that “hearing aids may not always be the best solution” for dementia patients. “Most premium hearing aids,” she observes, “are designed to be discreet, so they may be too small and too easy to lose for a patient with dementia, especially if they have dexterity problems. Hearing aids also require that a person (or their caretaker) remember to keep the batteries fresh and the device clean and in good working condition. Instead, assistive listening devices may work better.”²

¹ See “Hearing Loss and the Dementia Connection” (November 12, 2021), <https://publichealth/jhu.edu>.

² “Hearing Loss and Dementia: How Are they Related?” (August 3, 2021). See also Kim Tingley, “Can Hearing Aids Prevent Dementia?” *The New York Times Magazine* (Feb 20, 2020).

Grading Systems for VS

The following grading systems (Koos, Gardner-Robinson, and House-Brackmann) are useful, respectively, for classifying tumor size and involvement, hearing levels, and facial nerve function:³

The Koos grading system defines a Grade 1 tumor as those involving only the internal auditory canal. A Grade 2 tumor extends into the cerebellopontine angle, but does not encroach on the brainstem. A Grade 3 tumor reaches the brainstem and may deform the brainstem but does not shift the 4th ventricle, whereas a Grade 4 tumor deforms the brainstem and shifts the 4th ventricle.

The Gardner-Robertson grade (G. Gardner & J. H. Robinson, 1988) defines hearing grades. Grade I refers to good to excellent hearing [pure-tone average (PTA) 0-30 dB, 70-100% speech (SD) discrimination score]. Grade II refers to serviceable hearing [PTA 31-50 dB, SD 50-69%]. Grade III is defined as non-serviceable hearing [PTA 51-90 dB, SD 5-49%]. Grade IV refers to poor hearing [PTA 91-maximum, SD 1-4%], and Grade V is defined as deafness [PTA not testable, SD 0%].

The House-Brackmann scale (W. F. House & Derald E. Brackmann, 1983-85) defines facial nerve motor functions. Grade I is normal function. Grade II is mild dysfunction. Grade III is moderate dysfunction. Grade IV is moderately severe dysfunction. Grade V is severe dysfunction. Grade VI is total paralysis.

³ Source: “Stereotactic Radiosurgery for Vestibular Schwannoma: International Stereotactic Radiosurgery Society (ISRS) Practice Guideline,” *Journal of Radiosurgery and SBRT*, Vol. 5 (2017).

Access to Health Care in America: 'Racial Disparities'

The comprehensive study entitled *Access to Health Care in America* (Washington, DC, National Academies Press, 1993, 240 pp.) was prepared by the Institute of Medicine (U.S.) special Committee on Monitoring Access to Personal Health Care Services. The preface to the study states: "This useful volume defines a set of national objectives and identifies indicators – measures of utilization and outcome – that can 'sense' when and where problems occur in accessing specific health care services. Using the indicators, the committee presents significant conclusions about the situation today examining the relationships between access to care and factors such as income, race, ethnic origin, and location. . . This highly readable and well-organized volume will be essential for policymakers, public health officials, insurance companies, hospitals, physicians and nurses, and interested individuals." The special committee's findings and recommendations for improving "the situation" documented in 1993 can be read online (Google the book's title).

Since 1993, the problem of 'racial disparities' in the treatment of brain tumors has continued to be identified as a remediable part of the health care "situation" in America. The following are some recent medical journal articles (2009-2018) you can examine at www.PubMed.gov.

- W. Curry and F. G. Barker (Harvard Medical School), "Racial, Ethnic and Socioeconomic Disparities in the Treatment of Brain Tumors," *Journal of Neurooncology*, Vol. 93 (2009). "Disparities in American health care based on socially-defined patient characteristics such as race, ethnicity, and socioeconomic position are well-documented. Patients in disadvantaged groups are less often treated by high-volume providers. Mortality and morbidity of initial treatment are higher for brain tumor patients in disadvantaged groups, and they present with markers of more severe disease. Clinical trial enrollment appears to be lower among brain tumor patients from disadvantaged groups. We propose future research both to better define disparities and to alleviate them."
- D. Mukherjee et al (Johns Hopkins School of Medicine), "Disparities in Access to Neuro-oncologic Care in the United States," *Archives of Surgery*, Vol.145 (2010). "African Americans and Hispanics have disproportionately worse access to high-quality neuro-oncologic care over time compared with whites. Higher countywide median household income and decreased countywide poverty rate were associated with better access to high-volume hospitals, implicating socioeconomic factors in predicting admission to high-quality centers."
- S. McClelland et al (Boston Univ and Univ of Minnesota Schools of Medicine), "Morbidity and Mortality following Acoustic Neuroma Excision in the United States: Analysis of Racial Disparities during a Decade in the Radiosurgery Era," *Neuro-Oncology* (Nov 2011). "The Nationwide Inpatient Sample from 1994-2003 was used for analysis. Only patients admitted for acoustic neuroma excision were included. High surgeon caseload, private insurance, and younger patient age independently predict improved postoperative outcomes following acoustic neuroma excision. Although overall morbidity and adverse discharge disposition were similar regardless of race, African Americans were 9 times more likely to die following surgery than Caucasian patients over a decade-long analysis. Given the relatively benign natural history of acoustic neuroma and the alarmingly increased mortality rate following surgical excision among older patients, African Americans, and patients receiving care from low-caseload surgeons, acoustic neuromas in these patient populations may be best managed by more minimally invasive modalities such as observation, fractionated radiotherapy, and stereotactic radiosurgery. The authors state: "It is possible that the racial disparities in mortality from this study could be explained primarily by African

(Cont., p.5)

(Health Care ,Cont.)

Americans harboring larger tumors prior to surgical excision. . . Another important finding was the role of private insurance in patient outcomes. Patients with private insurance persistently had decreased postoperative morbidity following acoustic neuroma excision. . . Perhaps the most striking and correctable finding is the persistence of the impact of surgeon caseload in predicting outcome following acoustic neuroma excision. Whether the outcome measure was mortality, morbidity, or adverse discharge disposition, surgeons performing fewer than 3 excisions per year yielded significantly inferior patient outcomes than surgeons performing 3 or more excisions per year.”

- R. Babu et al (Duke University Medical Center), “Vestibular Schwannomas in the Modern Era: Epidemiology, Treatment Trends, and Disparities in Management,” *Journal of Neurosurgery* (July 2013). “In this study the authors describe the current epidemiology of VS and treatment trends in the US in the modern era. They also illustrate patient characteristics and elucidate their effect on tumor management. . . A total of 6,225 patients with VS were identified through the Surveillance, Epidemiology, and End Results database [SEER], spanning the years 2004-2009. . . with the majority of patients being Caucasian (83.16%). . . Increasing age correlated with decreasing use of surgery, whereas increasing tumor size was associated with the increased use of surgery. Older age was associated with an increased likelihood of conservative management. . . Racial disparities were also seen, with African American patients being half as likely to receive surgery and nearly twice as likely to have their VSs managed conservatively despite presenting with larger tumors.”

- M. Carlson et al (Mayo Clinic), “Racial Differences in Vestibular Schwannoma,” *Laryngoscope*, Vol.126 (2016). Using the SEER database, a total of 9,782 patients with VS were identified: 75.6% white, 8.2% Hispanic, 7.7% Asian, 4.1% black, 4.3% other. The annual incidence of VS was lowest among black and Hispanic populations. “Compared to white populations, black, Hispanic, and Asian were more likely to present with larger tumors. . . Hispanic patients were more likely than white patients to undergo surgery; however, there were no differences between white, black, and Asian populations with regard to treatment modality. Hispanic and black patients had the poorest overall survival following surgery compared to other groups. . . Further studies are required to determine which factors drive differences in tumor size, age, annual disease incidence, and overall survival between races.”

- C. L. Anzalone et al (Mayo Clinic), “Racial Differences in Disease Presentation and Management of Intracranial Meningioma,” *Journal of Neurological Surgery* (Dec 2019). A valuable SEER database study showing how “Issues of quality and equity in healthcare are complex.” . . . “Elective diagnostic imaging has been shown to be more accessible to patients with higher socioeconomic backgrounds and professional work experience. One commonly held belief is that the increasing incidence in meningiomas [the most common intracranial benign tumor] correlates with the availability of magnetic resonance imaging (MRI) scanners, and receiving MRI’s for other problems. The availability of MRI scanners may be vulnerable to racial disparity; however, it also may be the case that certain reasons to perform a head MRI may be more common amongst different ethnic groups.” For example, Caucasians with superior health insurance coverage may be more likely to have a MRI workup for headaches, resulting in identifying a meningioma. Low household income drives underdiagnosis and diagnostic delays with many minority populations.

Note: The Patient Protection and Affordable Care Act for lowering health care costs was signed into law by President Obama on March 23, 2010. See Healthinsurance.gov/obamacare.

Radiosurgery/Radiotherapy Review

Medscape.com is an online health information resource mainly for physicians and healthcare professionals. Its mission is to improve patient care by providing the latest medical news and perspectives about advances in medicine. For the website, Dr. Rodney C. Diaz (University of Colorado School of Medicine, retired) has prepared a review article entitled “Gamma Knife and Other Stereotactic Radiotherapies for Acoustic Neuroma” (February 24, 2021, 17 pp).⁴ The article’s section headings are: Radiation Therapy, Single-Dose versus Fractionated Treatments, Linear Accelerator versus Gamma Knife, Tumor Biology, Results and Complications of Single-dose Therapy, Results and Complications of Fractionated Therapy, Controversies of Stereotactic Radiotherapy, and Conclusions.

The article has a 3-page bibliography. For Gamma Knife radiosurgery special attention is called to the 2017 ‘Practice Guideline’ prepared by the International Stereotactic Radiosurgery Society, ISRS (See footnote No.3, above). Dr. L. Dade Lunsford (Leksell Distinguished Professor of Neurological Surgery at the University of Pittsburgh), who was a key founder and first president of ISRS (1991-93), has written a personal memoir about the development of this important society and the early history of stereotactic radiosurgery. He brought Gamma Knife from Sweden to Pittsburgh in 1987. “Radiosurgery,” he estimates, “became mainstream during the decade of 2000-2010.”⁵

“Every Experience is Different”

In her ‘Your Health’ article for AARP, Joyce Purnick, journalist and former columnist for *The New York Times*, describes her own experience with the cochlear implant (CI).⁶ Her serious hearing loss in both ears began in childhood, attributed to an overprescribed antibiotic. She finally turned to NYU Langone’s Cochlear Implant Center for hearing help and found she was a good candidate for the CI having a healthy, active auditory nerve.

She writes: “In September 2019, at age 73, I underwent surgery. My worse (left) ear would get the implant, and I would continue to wear a hearing aid in my right. . . Adjusting to the implant can take patients up to a year, sometimes longer. Every experience is different. . . My own reality? Conversations are back – no faking or withdrawing. I hear well in small gatherings but not so great in crowded settings with a lot of ambient noise. Amplified sound remains difficult. But the sound of speech is now close to what it was before my hearing loss – somewhat more robotic, but the voices of friends and family are fully recognizable. A new hearing aid in my better ear syncs with my implant. That improves my general hearing and streams sound directly into both ears, which lets me converse by cellphone and enjoy videos, podcasts and audiobooks. All that was impossible presurgery. Music, a more sophisticated sound than speech, is distorted for me. While intensive training helps some CI users with music, implants are designed for language and speech comprehension, not for Beethoven. I miss Beethoven. I miss hearing as I did when I was young. But as we all learn as we age, life is a matter of trade-offs. I was cut off from the world around me. Now I am back in the game. I’ll take it.”

⁴ <https://emedicine.medscape.com/article/857604-overview#showall>.

⁵ L.Dade Lunsford, “The Development of the International Stereotactic Radiosurgery Society,” *Journal of Radiosurgery and BRT*,” Vol.1 (June 2011).

⁶ “Turn the Sound Back On: How I Went from Being Almost Completely Deaf to Hearing Again,” *AARP Bulletin* (Jan-Feb 2022), pp.16-19.

ANA/NJ Virtual Support Meeting

Sunday, October 16, 2022

1:00 to 3:00 p.m. EST

TOPIC:

“Radiosurgery for Acoustic Neuroma: Using the New Icon Model Gamma Knife”

A presentation and discussion session with Q&A by Dr. Anthony D’Ambrosio, MD, who is Director of Neurological Surgery and Gamma Knife Radiosurgery at Valley Hospital in Ridgewood, NJ. Dr. D’Ambrosio is a member of our Medical Advisory Board. He is online at Neurosurgeons of NJ.

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Currently the Acoustic Neuroma Association of New Jersey (ANA/NJ) is limiting its educational meetings to virtual ‘Zoom’ opportunities. Please mark your calendars and plan to participate in this October 16, 2022 virtual support meeting with Dr. D’Ambrosio.

You do not need to be a resident of New Jersey or a particular area in New Jersey or a member of ANA/NJ to participate, but **you do need to register** [registration information below]. Family members, caregivers, friends, and interested persons are welcome to attend as well. Bring your questions and join peers for this interactive opportunity.

In order to receive a confirmation email with instructions for joining the meeting, please send an email to Dave Belonger at dbelonger@verizon.net requesting attendance on October 16.

We look forward to welcoming you!





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